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‘You are labelled by your children’s disability’ – A community-based, participatory study of stigma among Somali parents of children with autism living in the United Kingdom

Dr Lucy Selman^a, Dr Fiona Fox^{a,b}, Nura Aabe^c, Dr Katrina Turner^{a,b}, Dr Dheeraj Rai^{a,d}, Dr Sabi Redwood^{a, b}

^a School of Social and Community Medicine, University of Bristol, Faculty of Health Sciences, Canynge Hall, 39 Whatley Road, Bristol, BS8 2PS, UK

^b The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care West (NIHR CLAHRC West) at University Hospitals Bristol NHS Foundation Trust, 9th Floor, Whitefriars, Lewins Mead, Bristol BS1 2NT, UK

^c Autism Independence, 176 Easton Road, Bristol BS5 0ES, UK

^d Avon and Wiltshire Partnership Mental Health NHS Trust, Jenner House, Langley Park, Chippenham SN15 1GG, UK

Author email addresses: lucy.selman@bristol.ac.uk, f.fox@bristol.ac.uk, hello@autism-independence.org, katrina.turner@bristol.ac.uk, dheeraj.raai@bristol.ac.uk, sabi.redwood@bristol.ac.uk

Corresponding author:

Lucy Selman

School of Social and Community Medicine, Faculty of Health Sciences, University of Bristol
Canynge Hall, 39 Whatley Road, Bristol, BS8 2PS, UK

t: +44 (0)117 33 14570, f: +44 (0)117 92 87325

e: lucy.selman@bristol.ac.uk, orcid.org/0000-0001-5747-2699,
https://www.researchgate.net/profile/Lucy_Selman

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Abstract

Objectives: Social stigma is commonly experienced by parents of children with autism. Our aim was to understand the nature of stigma experienced by Somali parents of children with autism in the United Kingdom (UK), and to consider how they coped with or resisted such stigma.

Design: We used a community-based participatory research approach, collaborating with a community organisation of Somali parents. In-depth interviews with simultaneous translation were conducted with 15 Somali parents of children with autism living in Bristol, UK, in 2015. Parents were sampled purposively to capture diversity in children’s age, severity of autism and time since diagnosis. Directed thematic analysis used Link and Phelan’s model of stigma.

Results: Of the 15 participants, 12 were mothers (mean age 36). The 17 children with autism they cared for were 4-13 years’ old, and five were girls. Two main themes with sub-themes were identified: the nature of stigma (labelling and stereotyping; separation; emotional reactions, discrimination and power), and coping and resistance (the power of language; faith as a resource; learning, peer support and community relationships). Children with autism were labelled and stereotyped (e.g. as ‘sick’, ‘naughty’, ‘different’) and parents blamed for not controlling them, leading to social rejection and isolation. Stigma was associated with a poor understanding of autism, a lack of vocabulary related to autism in the Somali community, and prejudice against mental illness and disability. There was evidence of enacted and felt stigma and examples of discrimination. Finding their own language to

describe their child's condition and drawing on faith, learning and peer support were important resources in resisting stigma.

Conclusions: Findings inform support for this community, highlighting the need to raise awareness of autism, enable parents to speak openly, and ensure appropriate professional services and interventions are available.

Keywords

Autism, Somali, Immigrant, Stigma, United Kingdom, Community-based participatory research, Parent

Introduction

Autism is a neurodevelopmental disorder characterised by impairments in reciprocal social interaction and communication and restricted and repetitive patterns of behaviours and interests (Lai, Lombardo, and Baron-Cohen 2014). Children of migrant parents living in western countries are more likely to have an autism diagnosis than the general population, particularly autism with intellectual disability (Becerra et al. 2014; Bolton et al. 2014). Somali migrant populations carry a particularly high burden, although the mechanisms underlying this remain unclear (Magnusson et al. 2012; Hewitt, Gulaid, and Hamre 2013).

The developmental impairment presented by children with autism has implications for family dynamics and parents' well-being (Gardiner and Iarocci 2012; Karst and Van Hecke 2012). High levels of stress (Ericzon, Frazee, and Stahmer 2005) and depression (Zablotsky, Anderson, and Law 2013) and poor quality of life (Shu 2009; Yamada et al. 2012) have been reported among parents of children with autism, with mothers particularly affected (Gau et al. 2012). Despite the increased burden of severe forms of autism, there is limited evidence on the experiences of parents from migrant Somali populations. A previous study that included interviews with 38 Somali parents in Minnesota concluded that they are likely to have different experiences of raising children with autism than non-immigrant populations, and potentially greater support needs (The Autism Research Team 2014).

The social impact and stigma associated with caring for a child with disabilities can be more challenging for some parents than the child's impairments. Following Scambler (1998), 'enacted stigma' or discrimination refers to the experience of unfair treatment by others, while 'felt stigma' or self-stigmatization refers to the shame and expectation of discrimination that prevents people from talking about their experiences and seeking help.

The stigma experienced by parents of children with autism, and its negative effects, was first described by Gray (Gray 1994, 1993). Drawing on Goffman's sociological concept of 'courtesy stigma', Gray argues that parents' stigmatisation arises as a result of their association with, and responsibility for, their child with autism (Gray 1993). Other studies have demonstrated how cultural factors influence the nature and experience of stigma related to autism internationally (Mak and Kwok 2010; Hwang and Charnley 2010; Burkett et al. 2015; Shaked and Bilu 2006). However, despite the benefit of using an appropriate theoretical model in qualitative research on complex subjects (Reeves et al. 2008), much of this research is either atheoretical, or uses theories unrelated to stigma (Burkett et al. 2015). Furthermore, while stigma has been identified as an important feature of the experience of Somali parents of children with autism (Kediye, Valeo, and Berman 2009; The Autism Research Team 2014), no in-depth exploration of autism-related stigma within a Somali community has previously been published.

Our study aimed to inform service provision by improving our understanding of the experiences of Somali parents of children with autism living in Bristol, UK, using qualitative methods and a community-based participatory research (CBPR) approach (Minkler and Wallerstein 2011). While an overview of the study findings has been published elsewhere (Fox et al. 2016), stigma was identified as a key feature of the parenting experience which warranted further analysis. In this paper we explore the nature of stigma experienced by these parents and consider how they coped with or resisted such stigma, drawing on current stigma theory.

Study design and methods

The CBPR approach we adopted combines researchers' methodological and clinical expertise with community members' real-world knowledge and experiences in an equitable way (Cargo and Mercer 2008). We designed the study in collaboration with Autism Independence (AI), a local community organisation made up of Somali parents whose children have autism. Members of the organisation were involved throughout the research study: specifying the research questions, collecting data, developing recommendations from the findings, and dissemination. The organisations' chief officer (NA) played an active part in the research, and is an author of this article.

The qualitative design involved semi-structured interviews with Somali parents of children with autism. Interviews were conducted by co-interviewers: FF, a qualitative researcher, and NA, who interpreted between English and Somali.

Study setting

This study was conducted with Somali residents in Bristol, UK, a population estimated at 10,000 (Bristol City Council 2016). The second largest migrant community in Bristol, after Polish migrants, Somalis in Bristol are the fourth largest Somali community in the UK (Bristol City Council 2016).

Sampling and recruitment

Sampling was purposive, aiming for maximum variation based on children's age, severity of their disability, and time since diagnosis. We aimed to recruit approximately 15 parents of children under 16 years' old, a mix of mothers and fathers. This sample size was considered adequate to meet the exploratory study aims and attainable based on the authors' prior experience of working with this community.

Participants were recruited via AI's social media network. Parents interested in participating contacted NA, who provided the study information, which was co-produced in English and Somali.

Data collection

Face-to-face interviews were led by FF and supported by NA, who provided simultaneous translation, including reframing questions and prompts where needed. Parents chose to speak Somali, English or both in the interviews. Interviews were conducted in parents' homes or at a community centre, depending on participant preferences. Interviews were scheduled to accommodate prayer times, periods of fasting and childcare responsibilities. NA read through the information sheet with participants prior to the interview to ensure understanding and agreement before obtaining written consent.

A semi-structured interview schedule guided the interviews. The schedule was developed by the research team and members of AI, and explored parents' experiences of the trajectory of their child's condition: pre-diagnosis, diagnosis, post-diagnosis, access to and experiences of services, and adapting to and managing family life. Field- and debriefing-notes were taken during and after the interviews respectively and integrated into data analysis.

Interviews were digitally recorded and the spoken English transcribed verbatim by a professional transcriber. NA checked the transcripts and her simultaneous translation for accuracy by listening to the audio files, adding explanatory notes and elaborating on translations where necessary.

Research ethics

The co-researcher, NA, has a child with autism, is the chief officer of AI and a facilitator of education sessions for parents. Therefore she was known, but not close, to most potential participants. While this posed a threat to participants' anonymity and may have affected the data collected, we judged that the benefits of working closely with a community member with shared experiences outweighed potential limitations. NA had extensive experience of interpreting in healthcare settings, and training in qualitative methods and protecting confidentiality and privacy. We used guidance and resources on CBPR (National Coordinating Centre for Public Engagement 2012; Centre for Social Justice and Community Action 2015) to sensitise the research team to ethical research in CBPR. The study was approved by the University of Bristol (20001 FREC).

Analysis

Thematic analysis (Braun and Clarke 2006), a method for identifying, analysing and reporting patterns in qualitative data, was used owing to its potential to provide a rich descriptive account of complex phenomena. Analysis occurred in 4 stages: first, familiarisation with the data and inductive line-by-line coding (FF, NA) was used to create a coding frame, using a constant comparative approach (Glaser and Strauss 1967). Second, the coding frame was refined by other members of the research team (KT, SR, DR) reviewing transcripts, identifying themes, searching for negative evidence, making comparisons across the dataset and commenting on the coding frame. The following four main themes were identified: 'my child is different'; perceptions of autism; navigating the system; and support. Stigma arose across these themes as highly salient in parents' lives, so we continued with analysis to explore experience of stigma and coping mechanisms. In the third stage, we identified and reviewed all data related to stigma, and appraised these in light of Link and Phelan's model (Link and Phelan 2001, 2006) (LS), to ascertain whether it fitted the data and

would enhance further analysis. Link and Phelan (2001, 2006) conceptualize stigma as existing when six interrelated components converge (Box 1). Originally developed in social psychology, the model is now widely used, including in understanding autism-related stigma in other populations (Kinnear et al. 2016). As several of the inductively generated themes (e.g. relating to perceptions of/attitudes towards autism) were aligned with the model, we proceeded to the final stage of analysis: the model of stigma (Box 1) was used as an interpretative lens to further describe and organise the data.

[BOX 1]

Analysis was managed in NVivo (QSR International Pty Ltd 2012). Participants were given unique ID codes which are used when tagging anonymised interview excerpts.

Results

Fifteen parents of children with autism were interviewed. Interviews lasted 45-90 minutes. One parent declined to be audio-recorded, so detailed notes were taken during the interview.

Participant characteristics

Of the 15 participants, 12 were women. Despite our efforts to recruit fathers, only three participated, reflecting the traditional role of mother as primary carer in the Somali community and the reticence of some fathers to discuss autism. None of the men and women interviewed were partners. The mean age of participants was 36 (range 28-56) (Table 1). Participants came to UK between 1992 and 2012 (mean 10 years, 9 months ago). None of the 12 mothers were currently working. Of the nine married women, six reported that their

husbands were employed. Two of the three male participants were employed. On average, participants had five children (range 3-8).

[TABLE 1]

Between them, participants cared for 17 children with autism (two participants had two children with autism). The children ranged from four to 13 years (mean age 7). Five were girls. Parents described behavioural problems common in autism, such as children having “no sense of danger”, running away and having violent outbursts.

Stigma was a theme that ran through parents’ discussions of the impact of autism on their family’s life. Two main themes with sub-themes were identified in the data: the nature of stigma (labelling and stereotyping; separation; emotional reactions, discrimination and power), and coping and resistance (the power of language; faith as a resource; learning, peer support and community relationships).

1. The nature of stigma

Participants did not use the term ‘stigma’. However, parents described in rich detail components of stigma outlined in Link and Phelan’s model, particularly labelling, stereotyping, separation and emotional responses (both their own and encountered in the community). Although less common, incidents of discrimination, and the power on which these depend, were also described.

Labelling and stereotyping: ‘You are labelled by your children’s disability’

Parents described how they were seen as ‘different’ because of their child’s or children’s autism:

[One] of the reasons that people hide their children’s disability, and their children with disability, [is that] they are worried that people are going to say... ‘She’s the one

who has got a child with autism.’ Or... ‘She has got a child with no language, who doesn’t talk.’ You are labelled by your children’s disability. (PPT 3)

The same mother explained how depersonalising and upsetting it was when her son was labelled ‘ill’:

I met a lady in this place [who] was talking about my son and she said, ‘Your ill son.’ I was very upset that she called [him] my ‘ill son’, and I spoke to her quite unhappily: ‘Ask me by his name and don’t say, ‘How is your ill son?’’... He has got a name; he’s a person... It leaves you with burden that that’s how people see you... I don’t see my son that way. (PPT 3)

Central to being labelled as different, and the associated stereotyping, was a perceived lack of understanding and vocabulary related to autism in the Somali community. Several participants reported that there was no Somali word for autism, and that autism was poorly understood:

They can’t understand what autistic [means]... ‘Autism’, is a new word [for the] Somali community. (PPT 2)

However, one parent, an exception, thought that autism was becoming better known and accepted in the Somali community:

Before, they used to be very surprised, but now you can see people are beginning to hear about autism... You come across autism more now; people don’t see you different now. (PPT14)

Two features of autism were identified as particularly difficult to understand: the disruptive behaviour associated with autism and the invisibility of the condition:

Sometimes, when you're walking or even in the playground, he'll hit any child... Last week he hit a man, and I told him 'sorry', twice. He said, 'No, no, he hit me!' (PPT 15)

He doesn't come across different when we go out, so that hides it... People don't see him [as] different, so people don't really understand. (PPT6)

Reflecting widespread uncertainty regarding the status of autism as an identifiable condition, participants struggled to categorise autism, for example as either a mental illness or a disability. Both of these labels had negative associations for participants. One participant said that in Somalia there is *'nothing in between a normal person and mentally sick'* (PPT 2), highlighting how any deviation from 'normal' cognitive function and ability was understood as mental illness and had negative connotations. A mother explained that the word 'disability' was highly sensitive, and that children with mental disabilities were described using derogatory language, such as 'doqon' ('retarded'). She discussed her wish for her daughter to be educated separately from children with other disabilities.

Related to the difficulty of categorising autism was the lack of consensus on and understanding of its aetiology and trajectory. Parents received conflicting messages from members of their own community, with some insisting that their child would *'grow out of autism'* (PPT 5) and others recognising it as a lifelong problem. The suspicion that parents might in some way be implicated in causing their child's autism influenced other people's responses to them (see *Emotional responses*), as well as parents' self-perceptions:

Sometimes [parents] can't convince themselves that there's a problem with their child. They can be a bit in denial sometimes... They feel a bit guilty about it. (PPT 9)

Separation: 'You always meet a lot of difficulties out there'

Alongside labelling and stereotyping, participants described the social separation that occurred as a result of their child's autism. This separation, a hallmark of stigma, began with children being labelled sick, mentally ill, different or disabled, and led to their and their families' physical separation from others.

[Other families] separate my son from the other children. Like, he [has] a problem.

Like... 'Don't go near the sick child.' It's not a good thing for my son. (PPT 15)

Many parents had become socially isolated from the wider community. Some parents reported neighbours or friends avoiding their company, while others described how parents of children with autism isolated themselves to protect their children, or to avoid the difficult interactions they encountered when their children did not follow social 'rules':

We stopped going [to the youth centre] because [my son] doesn't understand sharing.

When he sits on the computer and another child comes and says, 'I'd like to use the computer'... He won't accept anyone using it. (PPT9)

Parents understood the social difficulties they encountered to be a direct consequence of the community's lack of understanding and acceptance of autism:

Sometimes he copes well in public, like indoor play spaces, and sometimes he won't...

It can be a problem because all the people don't understand what's wrong with [child]. He will scream loudly. He might take what they've got. So you always meet a lot of difficulties out there. (PPT 9)

Many parents also shut themselves off emotionally, and were unwilling to talk about their child with others. Participants' willingness to discuss autism with other people varied according to their stage of acceptance and their concerns about stigma:

I kept it to myself a lot. I thought, if I had the right people at the right time... But I wasn't convinced to tell anybody or to share with anyone what's going on. (PPT 7)

The extent to which self-imposed isolation and emotional withdrawal were due to felt stigma was unclear, but it is likely to be a contributing factor.

Emotional responses, discrimination and power: 'They don't say it, but I feel it.'

Examples of enacted stigma demonstrated others' emotional reactions to the child with autism and their parents, and the discrimination directed at them:

PPT 7: *They don't understand, they don't like to get involved. They show me [in] their body language, that they don't want anything to do... They want to be staying away from me.*

Interviewer: *Why do you think that is? Why do they want to stay away?*

PPT 7: *They don't understand how it is for me, and they don't like the way he plays and the way he acts. They then don't like me because of him, and that's why I don't go to their houses... They don't say it, but I feel it... I am not welcome in their houses.*

It was relationships with adults rather than other children that were difficult:

The children don't have a problem... they're sweet. But the adults, that's the problem.

(PPT 15)

Parents reported being blamed for their child's behaviour, feeling they were judged bad parents, and other people getting upset or angry with their child's behaviour:

Some people think that my son behaves badly. They think a child like that, there is nothing wrong with them... you need to teach him manners. (PPT 5)

One mother reported an example of overt discrimination from another Somali mother:

People around you sometimes call you names and get upset with you, the way that [my daughter] behaves... They look at you as if you've raised that. They call you names. [You] pass them while they're still talking about you. (PPT 13)

Asked to expand upon the name-calling, she said:

In the centre one day, I couldn't pass through some of the aisles of the queue because I was using the push chair, and there was a lady with a wheelchair who was calling me names, kept talking to me and calling me names. It was really difficult. I explained that I couldn't manage my daughter in that long queue so I was just waiting on the side until I got a chance to be served... I got really upset that day. (PPT13)

This highlights how parents of children with autism are vulnerable to discrimination from those in positions of more cultural power, particularly parents of children who do not have autism.

2. Coping and resistance

Despite parents' reports of rejection and discrimination, several participants emphasised that they were not ashamed of their child:

I'm not the kind of person who hides my child and I'm not afraid; I'm not ashamed that my son has autism... I don't care what other people think. (PPT 14)

Participants' accounts of how they coped with and resisted enacted stigma arose in three themes: the power of language; faith as a resource; and learning, peer support and community relationships.

The power of language: 'He's different, yes. He is delayed, yes, but he's the same as the other children.'

A child's diagnosis of autism triggered a process of adjustment for parents in which language, particularly the label 'autism', played a key role. Accepting a diagnosis of autism meant a parent accepting that their child was in some sense different from other children, and that this difference was not simply one of personality traits, but related to a specific condition. Acceptance of the diagnosis had benefits and costs. The benefits were access to

specialist support and schooling for their child, and having an explanation for the behavioural problems he or she displayed. The latter acted to prevent the internalisation of stigma:

When you accept [that] this child is different to the others, who cares what the other people say? (PPT 2)

However, it was common for family and community members (in Somalia and the UK) to resist the diagnosis and to deny that the child was different:

People say, 'Why are you saying something silly like this? He's a child, he will grow out of it. A lot of children can't talk at the normal age, why don't you wait? Don't go to the doctors.' (PPT 9)

A major cost associated with accepting a diagnosis of autism was therefore the risk of judgment and exclusion.

As a result of these factors, parents engaged in a complex negotiation of autism as a diagnosis. Fathers in particular seemed to struggle, with several mothers in the study describing fathers who denied there was a problem, were unsupportive, or left the family altogether. Other parents actively resisted other people's negative labels, such as 'ill', 'sick' or 'disabled', finding their own language to describe their child's condition (e.g. 'different' or 'delayed') and restore their child's relationship to others:

Even his sister doesn't know what's wrong with him... if I tell her, 'Oh, he's sick,' it will just put in her mind he is sick, and he's not. He's learning from how he's playing with her, they are absolutely fine together. If she heard that from the other children, she will think he has a problem... He's different, yes. He is delayed, yes, but he's the same as the other children. (PPT 15)

Faith as a resource: 'It's what Allah already wrote'

Islamic faith was a key resource many parents drew upon in coping with their child's autism. It provided parents with the strength to resist blame, find acceptance and maintain hope in the future. Participants expressed the belief that events are predetermined and supersede human will or free choice:

Faith is the number one thing. We believe... that everything that happens is written before you are born. This is something beyond our choice, so we accept it. (PPT 4)

One father stated that faith had helped him '100%' to come to accept autism and see it as 'just a small difficulty':

If you were building a house, and you were supposed to put small bricks in horizontal, and then you didn't do them the horizontal way and you did it a vertical way, everything will go up, but the shape will be different [to what] you expected, or [what] the engineer drew. With autism, I see it that way; they have to learn things a different way, but they will eventually become the person they're supposed to become. They're not going to be lesser than any other human being. (PPT 8)

Learning, peer-support and community relationships: 'I start to explain autism'

Learning and educating oneself about autism was another way in which parents resisted and countered the stigma they experienced. Two fathers had undertaken extensive research and wanted to learn more. Parents accessed information online, and/or through professionals. Many participants learnt about autism through talking to other Somali parents with children with autism, often through AI. Those who had attended a structured training course on autism for parents of newly diagnosed children found the information and peer support helpful:

I met other Somali families that I can speak my own language with, who have children same as mine... I felt comfortable when I came back, and relieved by talking to all

these families. There was an interpreter and it was explained... I've learnt quite a number of things that we didn't know before. (PPT 13)

The knowledge and confidence developed through education and peer support enabled some parents to help or advise others. A father described how he took time to increase his own understanding of autism in the community by teaching others about it:

[My son] shout and he cry and then he lay on the floor. And an old man in Somali he told me, 'Why he's shouting. Can you tell him quiet?' And I said, 'No, I can't say because he can't... This is what he feel. He want to tell me something now, so I have to listen.' And he said, 'Why do you listen?' And I start to explain autism and [it] takes maybe half an hour...to make him to understand what autism is. And he realise and now he knows. Every time we go with him, he says, 'Oh, he's the autistic one.'

(PPT 2)

Discussion

In this study of the experiences of Somali parents of children with autism living in the UK, labelling, stereotyping, separation and emotional responses related to stigma were highly evident. Stigma was associated with a lack of awareness of autism as a condition, little Somali vocabulary related to autism, and widespread prejudice against mental illness and 'invisible' disabilities. Lack of awareness of autism meant that children were labelled as badly behaved and parents blamed for not controlling them. Parents and their children were rejected for being 'different' owing to their children's challenging behaviour. This resulted in social isolation, with some parents hiding their children away from public view; felt stigma was likely to have played a role here, but was not discussed directly. There were also examples of subtle and overt discrimination. Parents described having to deal with denial of the existence of autism and minimisation of the problems they encountered by some members

of their community and family. Stigma was expressed through body language and conveyed to parents feelings of being blamed, disapproved of and unwanted which might indicate felt stigma. However, there was also evidence of how parents coped with and actively resisted stigma, through negotiating a diagnosis of autism, resisting labels of ‘sick’, ‘ill’ or ‘disabled’ which they encountered in their community, and finding their own language to describe their child’s condition. Faith, learning and peer support were important resources in resisting stigma.

We found that others’ perceptions of the behaviour of children with autism was a key factor in the nature of parents’ relationships with community members and the stigma directed at parents. A high degree of disruptiveness, the extent to which a condition strains and adds to the difficulty of interpersonal interactions, is common in autism. Disruptiveness is intimately linked to people's perception of the ways things ‘should be’. Scheff’s (1996) description of the social function of mental illness as involving ‘residual rule-breaking’ is helpful here: similarly, the behavioural manifestations of autism violate taken-for-granted rules. Stigma arises when reactions to such rule-breaking are inappropriate, harmful or unfair (Scheff, 1966). Autism-related stigma enforced community norms by imposing Somali cultural discourses around child development and disorder, often in opposition to mistrusted medical discourses, and social rules regarding children’s behaviour.

Our research supports the findings of other recent studies in Australia (Broady, Stoyles, and Morse 2015), Nepal (Heys et al. 2016), Pakistan and India (Minhas et al. 2015), China (Lu et al. 2015), the USA and Canada (Kinnear et al. 2016) that suggest stigma continues to be a significant challenge for many families of children with autism, irrespective of their ethnic and cultural backgrounds. Kinnear et al’s (2016) study in North America found that stigma and their child’s autism-related behaviours played the largest roles in making parents lives challenging. In the study by Lu et al (2015), stigma was implicated in Chinese parents’ low

self-esteem, social isolation and stress. Reasons for this almost universal experience of stigma may be related to the ‘explanatory models’ (Kleinman 1988) or narrative frameworks people use to make sense of disease and abnormal experiences and behaviours, by explaining their cause, effect and course. This body of research suggests that people unfamiliar with autism draw on explanatory models in which the behavioural manifestations of autism relate to parents’ moral failings or poor discipline. Such views pose significant barriers to parents with autism seeking timely support for their children, and to children and their families participating actively in their communities.

In contrast, the biomedical explanatory model conceives of autism as a neurodevelopmental disorder with a number of social and behavioural consequences. Other studies have found that parents of children with autism use biomedical concepts and language to address erroneous beliefs, mitigate stigma and discrimination and explain their child’s difference (Sarrett 2015). Farrugia et al (2009) found that parents experienced considerable enacted stigma, but successfully resisted felt stigma by deploying biomedical knowledge to articulate ‘unspoiled’ subject positions. The institutionalisation of biomedical knowledge within the autism community was reportedly critical to this process. In our study, two fathers adopted this strategy, sharing biomedical explanations with others in their community to raise awareness and reduce enacted stigma. However, our participants also indicated that there was distrust of western medicine in their community. In fact, among our participants withdrawing socially and drawing on religion seemed more relevant in resisting stigma than deploying biomedical knowledge. In particular, an understanding of Allah as ultimately responsible for one’s life helped parents resist shame or guilt regarding their child’s condition. Analogous strategies have been reported in other studies with parents of children with autism (Gray, 1993, 1994; Woodgate et al., 2008).

While our participants reported similar experiences of stigma as those in previous studies of parents of children with autism, enacted and felt stigma may be particularly harmful in the migrant Somali community, which bears a disproportionate burden of severe autism. Somali migrants fleeing civil war will often have gone through highly traumatic experiences. On arrival in the host country, poor living conditions, health inequality and poverty, as well as anti-Muslim attitudes and rhetoric, are common (Bhui et al. 2006; Rechel et al. 2013). Somali migrants are therefore likely to have few material, cultural and social resources, rendering them particularly vulnerable to exclusion as a result of raising a child with autism.

This study had both strengths and limitations. We chose to recruit a relatively small sample, which reflected our exploratory aim of achieving insight into this seldom heard group, and enabled in-depth analysis. Although the sample was in other ways diverse, we interviewed only three men. While the low number of male participants reflects the unequal division of caregiving in the UK Somali community, the fathers in our sample may be atypical. Our male participants were engaged in learning about autism, supported their children and shared their knowledge with others. This level of engagement contrasts with reports from other participants and from AI that many Somali fathers find it particularly difficult to accept their child's autism. This should be taken into account when interpreting our findings. The co-interviewer was familiar to participants, and this may have influenced the data collected. Her insider knowledge enhanced the quality of interviews by putting participants at ease and enabling them to speak in Somali. However, there were a few cases in which she was aware, owing to her prior knowledge, of discrepancies between what a parent discussed during the interview and the real extent of their difficulties. This was particularly true for parents experiencing the greatest hardships. The tendency to downplay problematic experiences means that parents' difficulties might be even greater than reported here.

Findings from the study have clear implications for the support of migrant parents with children with autism. To reduce health and social inequalities and improve outcomes for children and families, strategies to reduce stigma and bolster coping resources in the community are needed. Evidence from this study can inform work in this area. Raising community awareness of autism and how it affects children from Somali backgrounds, for example through theatre (Pavid 2015), must be the cornerstone of any strategy to reduce stigma. Third sector organisations such as AI are important vehicles for raising the profile of the condition and supporting parents to speak openly. Some participants in our study were able to do that, but many did not have the confidence to do so. To enable more open communication, developing a vocabulary around the condition is vital, and biomedical terms can help parents educate their family and friends and deflect stigma. However, it is important that the community develops its own vocabulary and understandings of autism to prevent mistrust and denial, as efforts to impart biomedical knowledge might risk alienating communities further.

Creating spaces where children with autism can safely play or be with others will counteract parents' anxiety about their children's behaviour and social withdrawal. This can be achieved only if their atypical behaviour is understood and a wider range of community members are trained in how to manage such behaviour in ways that are not judgemental or punitive. Professionals in education, health and social care also have a role to play in tackling stigma, by responding sensitively to explanatory models in use in migrant communities that are disproportionately affected by autism. Finally, the design of interventions and services must be underpinned by an awareness of the evidence that studies such as this provides of the deleterious social effects of stigma on affected children and their families.

In conclusion, we found evidence that Somali parents of children with autism experienced considerable stigma, in the form of labelling and stereotyping, as well as more overt forms of

discrimination, leading to social exclusion and isolation. Supporting Somali parents to deal with stigma requires raising awareness of autism within the community, facilitating peer support, and building on parents' existing coping resources.

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Disclosure statement

The authors report no conflicts of interest.

Key messages:

1. Somali parents of children with autism living in the UK experienced labelling, stereotyping, separation and emotional responses related to stigma, associated with a lack of awareness of autism as a condition, little Somali vocabulary related to autism, and widespread prejudice against mental illness and 'invisible' disabilities.
2. While other ethnic groups report experiences of stigma in relation to raising a child with autism, enacted and felt stigma may be particularly harmful in the migrant Somali community, which bears a disproportionate burden of severe autism.
3. Raising the awareness of autism in Somali migrant communities and how it affects children and their families must be the cornerstone of any strategy to reduce stigma.

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Table 1: Participant characteristics

Participant ID	Gender	Age group	Relationship status	Age of child with autism	Total number of children, position of child with autism	Speech	Language interview conducted in
PPT1	F	26-30	Separated	4	5, 3 rd	Non-verbal	Somali
PPT2	M	36-40	Married	6	4, 2 nd	Non-verbal	English
PPT3	F	46-50	Married	12	7, 5 th	Started talking age 5	Somali
PPT4	M	56-60	Married	13	6, 4 th	Non-verbal	English
PPT5	F	36-40	Married	7	7, 5 th	Has started talking	Somali
PPT6	F	26-30	Married	5	3, 1 st	Non-verbal	Both
PPT7	F	31-35	Separated	7	3, 2 nd	Talks in words, not sentences	Both
PPT8	M	26-30	Separated	5	3, 1 st	Non-verbal	English
PPT9	F	31-35	Married	6	4, 3 rd	Talks a little	English
PPT10	F	46-50	Married	14	8, 5 th	Talks, taking some GCSEs this year	Both

PPT11	F	26-30	Married	4 (twins)	4, 1 st	Talk, 1 twin more severe than the other	Somali
PPT12	F	31-35	Married	8	4, 2 nd	Talks	Somali
PPT13	F	41-45	Married	9, 5	5, 3 rd and 5 th	Oldest mild, younger more severe (has a few words)	Somali
PPT14	F	36-40	Separated	9	7, 3 rd	Doesn't talk	Somali
PPT15	F	26-30	Married	5	3, 2 nd	Talks a little	English